# ALERT

**News from the UFMCC on AIDS Legislation, Education, Research and Treatment.**

**NOVEMBER, 1988**

## AIDS VIGILS HELD THROUGHOUT UFMCC

For the third year in a row, churches all over the Universal Fellowship of Metropolitan Community Churches have been holding weekend AIDS Prayer Vigils. MCC Toronto, MCC Dallas, Grand Rapids MCC, Angel of Hope MCC in Green Bay, Wisconsin, and Good Shepherd MCC in Highland, CA are among the many churches who have participated in this growing tradition.

The AIDS Prayer Vigil was originally conceived and conducted by Rev. David Farrell, and PWA Paul Burdette at MCC San Diego. The event brought church leaders from many faith backgrounds to MCC. Not all came to participate in solidarity with persons with AIDS. There was a group of fundamentalist protesters outside, resulting in a great deal of media attention, including a strong TV editorial condemning the protesters and acknowledging MCC for its unique position in this crisis.

The next Fall, Rev. Farrell brought the Vigil to the entire Fellowship via a well-produced "how-to" package, including a video presentation on the original Vigil. Churches all over the Fellowship observed the Vigil on the same weekend, in September, 1986.

This Fall, AIDS Prayer Vigils are being held almost every weekend somewhere in the Fellowship. People sign up to pray at the church for one or more hours (throughout the 50 hours) for persons with AIDS and their loved ones and caregivers. Full worship services are held at intervals throughout the weekend, and the usual Sunday morning or evening worship is incorporated into the Vigil.

Many churches also use the weekend as an opportunity for AIDS education, and sponsor seminars on prayer treatment, spiritual approaches to wellness, and meditation and visualization. Panels of people with AIDS, their families, service providers, and a medical update are frequent features. The weekend prayer vigils often attract a number of new people to MCC.

AIDS Prayer Vigils serve as excellent opportunities for ecumenical relations. Rev. J.E. Paul Breton, AIDS Vigil Coordinator at Good Shepherd MCC in Highland, CA, reports that their vigil is bing sponsored not only by the local MCC, but also by the San Bernardino Clergy Association, the Riverside Interfaith Fellowship, the Interfaith AIDS Council of the Inland Empire, and the Inland AIDS Project.

*(Continued)*

Rev. Steve Pieters, who travels to preach at many AIDS vigils, reports that sometimes attendance is less than the local staff might have hoped. "Denial is still deep in many places," Pieters reports. "Many people are tired of hearing about it, and this can reflect on attendance. At one large church, after a handful of people showed up for the Friday and Saturday vigil services, the pastor asked his usual large Sunday morning crowd if there was anyone left who did not know someone who had, or had died from, AIDS. When no one raised a hand, he exclaimed, 'Then where have you all been this weekend?' The closing service that night witnessed an exposion in attendance."

"So many issues divide the people of God, but in one thing people of Faith have always been united--our belief in the power of God, through our prayer, to being healing and hope to the suffering, the ill, the dying, and the bereaved." This message has gone out from all around the UFMCC to people of many different faiths. In the face of AIDS, we are building bridges never before possible.

## NEW DRUG DEVELOPMENT IN THE U.S.: AN FDA REPORT

An FDA Consumer Special Report on New Drug Development in the United States, dated January 1988, is being distributed to all members of the National AIDS Network, to educate the public about FDA drug research process. The report begins with an article by Frank Young, Commissioner of Food and Drugs, explaining the cumbersome U.S. drug development and approval process, and why they feel these "safeguards" are necessary, while acknowledging that "the terrible AIDS epidemic has brought a new urgency to thousands of Americans who, tragically, simply do not have long to wait for medical discoveries."

There are several helpful articles such as "A Skeptic's Guide to Medical 'Breakthroughs,'" "How to Enroll in a Drug Study," and "The Evolution of U.S. Drug Law."

In "Fast-Tracking the First AIDS Drug" an FDA press officer interviews two FDA doctors about the development of AZT, and the "unprecedented...attention and resources" the government has allotted to AIDS research, echoing the Reagan administration's stand.

Copies of the 60-page report may be obtained by writing the U.S. Food and Drug Administration (HFI-40), 5600 Fishers Lane, Rockville, MD 20857.

## HIV LATENCY PERIOD MISUNDERSTOOD

The AIDS/HIV Record of September 29, 1988 reports on a study which reveals that Americans do not yet understand that a person can be HIV-positive without exhibiting any symptoms. The study, conducted by The Public Agenda Foundation, used focus groups in six major US cities to provide insights into public attitudes and knowledge about AIDS.

Findings included that most participants understood the basics of HIV transmission, including the fact that it is not casually transmissable, and felt that confidentiality should be maintained in schools and in the workplace.

Most of the persons studied did not view AIDS as a moral issue, and did not think a "pre-1960s morality" was a viable approach to the problem, although they opposed needle exchange programs and providing condoms for high school students. The majority supported advertising condoms on TV, as well as clear, explicit education in public schools. Many favored mandatory testing for prisoners and hospital patients, as well as contact tracing and notification of those possibly infected.

For copies of The Nation Reacts to AIDS: A Report from Six Cities write to Julia Dolan, The Public Agenda Foundation, Six East 39th Street, New York, NY 10016.

## ALSO FROM THE SEPT. 29 AIDS/HIV RECORD:

...Researchers at the National Institute of Allergy and Infectious Disease (NIAID) and the National Cancer Institute (NCI) have linked soluble CD4, the receptor by which HIV enters cells, to a toxin, Pseudomonas, thereby producing a recombinant protein (CD4-toxin). It is hoped that this will be an effective therapy for HIV infection, by enabling the killing of HIV-infected cells, which does not happen with the use of CD4 alone. Initial trials of CD4 alone began in August.

...In a report from the Mental Health Research Institute of Victoria, Melbourne, Australia, Jon Currie, FRACP, states that eye movement abnormalities may be an early indicator of HIV-related neurological dysfunction. This would be a non-invasive technique to select high-risk patients needing early antiviral treatment, and to monitor on-going neurological status in persons with HIV infection.

...A report from Los Angeles indicates that ozone can be hazardous to condoms. Ozone is a major component of smog and a product of lightning storms. In a study at the University of Southern California, it was shown that a 72 hour exposure to ozone equivalent to an LA Stage One Smog Alert caused performations in 18 out of 20 unpackaged condoms, and that 11 of the 20 burst under small amounts of pressure. Condoms that were stored in intact plastic packages did not deteriorate.

*(Continued)*

...UCLA School of Public Health Study reveals that instructions for use on condom packaging are too difficult for anyone with less than a high school graduate reading level. Easily understood instructions are necessary to optimize the effectiveness of condoms in preventing the spread of HIV and other sexually transmitted diseases. The study has obvious implications for public education about HIV transmission.

## BUDDY GUIDE AVAILABLE FROM NAN

A new guide to putting together a buddy program for people with HIV infection is available from the National AIDS Network (NAN). Information includes volunteer receuitment, screening, training, supervision, burnout, suggested program policies and management forms. Write for Buddy Program: Volunteer Peer Support Programs for People With HIV Related Illness to: Clearinghouse, NAN, 2033 "M" St., NW, Suite 800, Washington, DC 20036. The Price is $5 for full NAN members, $10 for contributing members, and $15 for everyone else.

## SYMPOSIUM: Nov 11-13, 1988

"Representing AIDS: Crisis and Criticism" an interdisciplinary conference on the impact of the AIDS crisis on contemporary art, culture and thought.

Friday evening to Sunday noon - London, Ontario, Canada (halfway between Detroit and Toronto) $50.00 Canadian funds.

There will be 15 speakers (including John Greyson, California Institute for Art; Douglas Crimp, October Magazine; Simon Watney, Terrence Higgins Foundation - U.K.; Margaret Somerville, McGill U;) will present papers for discussion dealing with the following themes: Sexuality and Cultural Activism, AIDS Videos, Visual Arts, Philosophy Politics and the Law, the Literature of AIDS.

For Registration information contact: The Office of Continuing Medical Information, University of Western Ontario, London, Ontario, Canada, N6A 5C1; (519) 661-2074. For hospitality information contact: Clarence Crossman, Services Coordinator, AIDS Committee of London, 256 Oxford St, E., Suite 4, London, Ontario, Canada N6A 1T7; (519) 434-1601.

## VISUAL AIDS

"Visual AIDS" is a poster art show with as many as 200 AIDS posters from over 20 countries world-wide. This fascinating collection of posters presenting a variety of AIDS themes had its first opening October 12-20, 1988, at the London Regional Art Gallery, London, Ontario, Canada.

Inquiries about bringing the show to your area or adding posters from your area to the growing collection should be submitted to: Clarence Crossman, Services Coordinator, AIDS Committee of London, 256 Oxford St. E, Suite 4, London, Ontario, Canada N6A 1T7; (519) 434-1601.

## CONGRESS APPROVES COMPREHENSIVE AIDS LEGISLATION

Washington, DC, October 13...In the closing moments of the 100th Congress, the U.S. House and Senate passed an ominbus health bill that includes the nation's first comprehensive plan for fighting AIDS. Passed by voice vote, the bill -- S.2889, the Omnibus Health Amendment Act -- contains the result of negotiations between both houses over AIDS legislation passed earlier in the year.

Vic Basile, Executive Director of the Human Rights Campaign Fund (HRCF), hailed the passage of the AIDS legislation as "an extremely important first step toward the long-overdue national battle-plan against AIDS."

"This bill is especially critical to people with AIDS and HIV infection because it offers them hope that drugs will begin to move more quickly through the research process and become available to sick people as early as possible," added Basile.

Basile also noted the importance of the bill's anonymous testing and public education provisions for preventing new cases of HIV infection, while regretting that the bill does not include the comprehensive program of voluntary, confidential testing earlier passed by overwhelming margins in the House.

Senator Jesse Helms (R-N.C.) had threatened to kill the bill by tying up the legislation with obscure parlimentary maneuvers. Through skillful negotiations and a massive lobbying and media campaign, proponents of the bill moved the legislation through the House and Senate in spite of Helms.

"Congress has soundly rejected AIDS hysteria and quick fixes and has opted instead for a sensible and serious response to this public health crisis," said Basile. "With 40,000 dead and 1.5 million infected, this action comes not a moment too soon."

AIDS activists credited Senators Kennedy and Hatch and Representatives Waxman and Madigan for moving the bill, and cited their hard work and persistence in the closing hours.

The AIDS package passed includes these elements:

--Authorization for medical research, including most research provisions of both bills. Research highlights:

- 780 new personnel slots for the Public Health Service set aside for AIDS work;
- 9-month deadline for award of AIDS research grants and contracts;
- 21-day response time for resource requests from AIDS research agencies;
- Special authorities to the National Institute of Allergy and Infectious Diseases for construction and acquisition of facilities, training of personnel and other actions;
- New mechanisms to encourage clinical trials and early access to experimental AIDS treatments;
- Model protocols for care of HIV-infected persons.

*(Continued)*

-- Authorization for AIDS education programs at the federal, State and local levels. Authorized spending is at least $270 million a year through fiscal 1991. At least $30 million is reserved for education targeted to minority communities. The bill allows use of paid advertising in public education programs.

-- Two-year authorization for health-care demonstration programs, including home health and sub-acute care -- $110 million a year.

-- Two-year authorization for anonymous HIV testing and counseling, through grants to States at $100 million a year.

-- A two-year national advisory commission on AIDS.

## CWA CLINICAL TRIALS EXPANDING

The National Institute of Allergy and Infectious Diseases has established a new program that will greatly expand clinical trials of experimental drugs in children with AIDS (CWA). The Institute has awarded $8.8 million to 11 medical centers that will join NIAID's nationwide network of 34 AIDS Clinical Trials Units now conducting AIDS treatment research.

Since 1981, more than 100 children in the United States have been diagnosed with AIDS, and two or three times that many are believed to be infected with the human immunodeficiency virus (HIV), the cause of AIDS. Nearly all pediatric AIDS cases are caused by transmission of HIV from pregnant women to their unborn children.

Like adults, children with AIDS develop life-threatening opportunistic infections. Such infections are caused by other viruses, bacteria, parasites, or fungi that are usually fought off successfully by people whose immune systems are functioning properly. Children rarely have the AIDS-related cancers seen in adults with HIV infection. However, HIV-infected children typically develop severe, frequently recurring bacterial infections because their immune system are unable to manufacture specific antibodies.

During the past two years, ACTG investigators have been conducting several clinical trials of experimental therapies in HIV-infected children with symptoms of AIDS. They are evaluating the effectiveness of the antiviral drug AZT in countering HIV activity and intravenous gamma globulin in reducing bacterial infection. The pediatric units will conduct studies of promising new experimental therapies as they become available.

In preparation for possible early intervention studies, the units are expected to develop ways of identifying HIV infection in fetuses and infants. Commonly available tests do not distinguish between antibodies the child generates against HIV infection and antibodies transmitted from the mother that will eventually disappear. Recently, scientists have reported on a new technique, still in the research stage, that can aid in distinguishing between true and apparent infection in babies born to infected mother.

## LAZARUS MINISTRIES' BOOK PRICE INCREASE

Lazarus Ministries, the Mid-Atlantic District ministry of hospitality for people affected by AIDS, has announced a price increase for the book, Pastoral Ministry in the AIDS Era. Written by Lazarus Ministries' Project Coordinator, the Rev. Louis F. Kavar, this book is a thoughtful examination of ministry with the families and friends of people with AIDS.

Following a several month period during which Lazarus Ministries made this book available to the Fellowship at a wholesale price, the book will now be available at the cover price of $7.95 per copy plus a postage and handling charge of $1.25 for the first copy, 25¢ each copy thereafter. Discounts are available to church bookstores. Checks should be made payable to the Mid-Atlantic District, and orders sent to Lazarus Ministries, P.O. Box 8739, Pittsburgh, PA 15221.

## WOMEN'S AIDS SERVICE PROGRAM BEGINS

*(from AIDS Treatment News, Issue 65, 9/23/88)*

The San Francisco AIDS Foundation has received special funding to serve women with AIDS and ARC, and their partners and children. This program, possibly the first of its kind in the nation, is already serving 80 women.

Women with AIDS have faced unique, severe problems. For example, only five of the 80 clients in this program are now on AZT, and only five are on aerosol pentamidine. Only two of the 80 are now using an experimental treatment, such as dextran sulfate or AL 721.

Seventy of the 80 are low income; food and rent bills must compete with treatment costs. Many women are uninsured or underinsured. Women are often excluded from trials of experimental drugs. Long waits in public clinics are often impractical for women with young children and no childcare. Women with AIDS seldom have the community support and institutions available to gay men. Because of these and other obstacles, women with HIV-related symptoms are often late to receive treatment.

The new program runs ongoing discussion groups for sharing treatment and other resource information. With the help of Catholic Social Services and the Shanti Project, it hope to open two houses for women with AIDS or ARC.

For more information about this program, call Catherine Maier, its director, at the San Francisco AIDS Foundation. (415) 864-5855.

## AUTOPSY STUDY PINPOINTS DIAGNOSIS FAILURES

*(from AIDS Treatment News, Issue 65, 9/23/88)*

*(by John S. James)*

A study of autopsy records at two major New York hospitals found that half of the persons who died of AIDS had cytomegalovirus (CMV) infections not suspected while they were alive. Several other opportunistic conditions were also undiagnosed; three quarters of the patients who died were found to have unsuspected AIDS-related complications.

This study, published July 9 in The Lancet by researchers at the New York University School of Medicine, New York City Department of Public Health, and New York Hospital-Cornell Medical Center, can help physicians by letting them know which complications are most often missed, so that they can check carefully for these, especially in patients with undiagnosed problems.

Of all AIDS death records between May 1981 and May 1987 at two large teaching hospitals, one public and one private, 101 adult patients had autopsy and all other records available. The major unsuspected AIDS-related conditions were:

CMV infection, 49 percent (of all 101 cases);
Systemic fungal infection, 20 percent
Systemic KS, 14 percent;
MAI infection, 11 percent;
Systemic herpes infection, 9 percent.

Other problem diagnoses were fungal pneumonias (undiagnosed despite bronchoscopy and even biopsy), tuberculosis, and central nervous system lymphomas (sometimes treated unsuccessfully as toxoplasmosis).

Bacterial pneumonias--presumably treatable--were important contributors to death in 30 percent of the patients.

Successful diagnosis was found for pneumocystis (over 90 percent of cases), and cryptococcal infection and CMV retinitis (diagnosed correctly in all cases).

Previous autopsy studies (when the cause of death was not AIDS related) have also found that many infectious diseases are missed.

For more information, see Wilkes, MS and others, "Value of Necropsy in Acquired Immunodeficiency Syndrome", The Lancet, July 9, 1988, pages 85-88.